

IMMUNIZATION REGISTRY FOCUS GROUP STUDY

September 21, 1998

American Indian, Lower Education

Tucson, Arizona

Moderator: Gale Marshall

SECTION 1: GENERAL IMMUNIZATIONS AND HEALTHCARE

I. Prevention

Diseases mentioned:

- AIDS
- Hepatitis
- Measles
- Chickenpox
- Mumps

II. Immunization

A. *Reasons to get vaccinated*

- To keep children healthy
- To get into school

If they get it they won't get is as bad as if they didn't have a shot.

They're still going to get colds and all that. We can't prevent all that. We can to a certain extent.

B. *Reasons not to get vaccinated*

- Lack of education
- Fear of physical reactions/allergies
- Neglect

Sometimes they know and don't do it. Some are scared to.

Some don't have the education like what shots their kids receive or how that's going to affect their kids and prevent them from getting hurt.

Some mothers don't like to see their children go through pain, so they don't take them. Maybe the first time they take them and then they don't want to take them anymore.

They may not like to talk to the doctor and the doctor might ask Why haven't you brought your kids and they might not have a reason and they don't want to go through that embarrassment.

B. Ways parents are reminded of vaccine schedule

- Doctor gives pamphlet at baby's check-up
- Shot record booklet
- Letter from school
- Get a card from hospital when baby is born

With older kids we don't know until something happens—if they have a physical or an accident or something and then they tell us, did you know that your child needs this and this and this? I think it would be better to have a schedule for us or something.

D. Methods of easier tracking

- Ages of children included in booklet
- Two booklets for infants and school-age children

My son has had it three times, because they have it at Headstart and have it at the clinic and then sometimes they don't get the right information. He had the hepatitis series three times.

Wouldn't it be easier to have one national registry like the Center for Disease and whatever?

SECTION 2: IMMUNIZATION REGISTRIES

I. Initial reactions to the idea of a registry

Respondents reactions were neutral to positive.

Don't they have this information in the file---in the kids file? The information is kept in a medical file?

No one had heard of this type of registry before this focus group.

II. Content of the registries

A. Initial reactions to the type of information typically in a registry

Respondents had very little reaction either positive or negative, but had more questions.

Would you also have a signal if there is a reaction to the vaccine?

How long is this going to last? At what age do you stop following?

I think they should put down who did it. Who gave the shot. The actual person.

B. *Reactions to including home address and telephone number*

Respondents generally agreed that this was important information in order to be contacted.

C. *Reactions to include parent or child social security number*

Reactions varied from positive to negative. On one hand, there was a concern about the potential for fraud associated with Social Security numbers. On the other hand, another participant noted the SSN could be used as an identifying factor for children with the same names.

D. *Reactions to including healthcare members enrollment (WIC, Medicaid numbers, tribal enrollment number)*

Respondents expressed no concerns about this information being included.

III. Access

A. *Who should have access*

- Doctors
- Schools
- Day Care/Child Care facilities
- WIC
- Fire Department

B. *Who should not have access*

- Health Insurers
- Researchers
- Respondents were mildly skeptical about researchers. Most agreed that if it was for a positive purpose they would support researchers having access. There was also concern that health insurers could prevent them from obtaining health insurance.

If it is something just for data, just for statistics, I don't believe in that.

I, myself, don't believe in research and surveys and all that kind of stuff. I have this idea in my head that we are guinea pigs and a lot of things have happened that enforces my opinion of that, so it would kind of bother me.

C. *Reactions to idea of linking registry by computer to other health information systems*

Some thought the links would be acceptable because the systems mentioned are health-related. Other saw different advantages to such links, suggesting that the information be

linked to Poison Control and 911 systems so that the information would be available if the parent could not be reached or a parent is too distressed to answer questions.

To me the stuff on here is not secret. It's not a big deal. It's not like something your trying to hide or you don't want people to know.

It saves you from having to answer so many questions.

IV. Consent and Inclusion

A. Reactions to “opting out” option

Reactions were positive to the opportunity to opt out if desired. A few respondents expressed concern that the opt out notice might get lost in mail.

B. Reactions to “consent” option

Respondents recognized that some parents might feel like they had more control with this option. They also noted that with consent some parents may be more aware of immunization needs.

I think that if they give consent at the same time they'll give more information.

C. Reactions to “automatic” option

Negative reactions were expressed to not having a choice or being able to opt out in case of special circumstances. There were several comments about the possibility of information, such as an address being accessed by people which might result in “kidnapping” as in the case of a nasty divorce.

I think people like to know they have a choice.

SECTION 3: WRAP UP AND CLOSING

I. Most important benefits of registries

- Quick access to all the information needed
- Information in the hands of the right people
- Wouldn't have to carry immunization record books
- Could prevent duplication of immunizations
- Parents do not have to locate records in a messy house

II. Greatest concerns/biggest risks

- Information getting into the wrong hands

- There was no reaction to moderator' prompts concerning denial of health care, or denial of entry into day care or school.
- The moderator prompt concerning custodial issues and law enforcement elicited mild concern from a few respondents.

III. Influence of healthcare provider in decision to participate in a registry

- Respondents were more concerned if their physician did not support a vaccine.
- One respondent said the final decision lies with her.

IV. Suggestions/comments to people who are responsible for how system works

The respondents agreed that a registry was basically a good idea and preferred the idea of having a choice. Who would have access to the information in the registry was a major concern.

I would just like to know beforehand who's going to be getting this information and be sure it doesn't fall into the wrong hands. With everything else, I'm fine.

I think the registry is a good idea, but with certain restrictions. That the information be kept within certain boundaries, clinics, doctors, schools, and especially agencies concerning health. That prior notification will be sent out if information will be given to other department agencies, especially not regarding health, quote, unquote, like research.